

# APPGA meeting

## Impact of coronavirus on autistic people

### Minutes

Thursday 14 January 2021, 10.15-11.25



#### **Opening remarks from the APPGA Chair – Dame Cheryl Gillan MP**

- Many MPs have been contacted about issues faced by autistic people and their families
- APPG understands these problems – as an MP, highlighted some of these issues to the Prime Minister at PMQs next week
- *Left Stranded* report shows impact of the pandemic – on mental wellbeing, and the inequalities faced by autistic people
- Need to ensure we are communicating these issues clearly to Government – important we know when this lockdown will end

#### **Presentation of *Left Stranded* report findings - Jane Harris, Director of External Affairs, National Autistic Society**

- Presented NAS's *Left Stranded* report – the impact of the coronavirus pandemic on autistic people
- Report, supported by four other leading autism organisations, lays bare widening inequalities
- NAS ran online survey for autistic people and their families across the UK to tell us about experiences of coronavirus and pandemic
- Ran through of some of key findings:
  - o Compared to general public, autistic people in June and July were seven times more likely to be chronically lonely
  - o Autistic people in June and July were six times more likely to have low life satisfaction
  - o Mental health services stopped seeing many, including children
  - o Seven in ten parents said their children had difficulty understanding or completing school work
- This led to key recommendations in the report including:
  - o Publish the delayed autism strategy
  - o Include autistic children's needs in the national SEND review
  - o Invest in mental health and social care services
- Need to ensure we don't end up with a generation of people whose wellbeing is worse in the long run
- APPGA will send round slides after meeting so attendees have them
- Attendee raised issue of difficulty accessing PIP – will add this to APPGA's asks
- Attendee raised issue of ensuring APPGA meetings represent the full autistic community, including those from BAME backgrounds

**Dame Cheryl Gillan:** Parliamentary protocol means MPs cannot take on cases that don't relate to their own constituents – if you have an issue, it's important to approach your own MP first, as well as organisations like the NAS

### **Remarks from Kiri-Lynn Gardner, autistic adult**

- Have experienced mixed emotions and struggles during pandemic
- Mother of teenager with autism, works in education as an autism specialist, a 1:1 Teaching Assistant and an Activities Coordinator in a boarding school
- As a parent, impact on family life has been one of the hardest – son has experienced increased anxiety with no mental health support. Waiting list for CAMHS is now three years
- There is a lack of understanding and public awareness – have had colleagues in school complain about her difficulties with wearing a mask
- There has been disruption to routine and this has been hard for families to deal with – feel more isolated now than ever before
- As an autistic woman, feels she is having to prove herself a lot
- Mental health professionals don't seem to be trained in autism and this is difficult when the support is actually there
- Raised issues of accessing PIP

### **Remarks from Minister for Social Care, Helen Whately MP**

- Appreciate Kiri-Lynn sharing openly experiences of the pandemic, and is aware of the bigger issues around this
- Often attend meetings to speak but it is helpful to hear from people like Kiri-Lynn to gain insight
- Can only acknowledge how pandemic has been hard for people across the board – but some of those hardest hit are autistic, including restrictions, loss of structure/routine and things to manage anxiety
- Appreciated uncertainty – whether school is going to be open etc – can cause problems
- Pleased that the majority of special schools have stayed open
- Loss of services and support for those who rely on day services, respite etc – has sought to open these up and assist with infection control
- Have tried to make sure there is a voice for autistic people and people with disabilities, to better understand the impact of the pandemic
- Kiri-Lynn raised issue of masks – it's important for the Government to keep highlighting this and increase understanding of the fact that not everyone can use masks
- DHSC is working on improving understanding of autism, including through the Oliver McGowan mandatory training – details of things like this will be in autism strategy published in spring
- Important that people do not feel forgotten – there are people working across Government to try and make things better. This won't happen overnight but they will learn lessons of pandemic

### **Questions to the Minister:**

**Trevor: Does the Government's "levelling up" agenda include levelling up society for autistic people? We have been one of the groups most adversely affected by the pandemic but even before coronavirus struck autistic people suffered much health inequality, below average life expectancy, much lower employment and income**

**levels and discrimination in the criminal justice system. How does the Government intend to level up society for autistic people thus making our lives better?**

- This is one of Government's focuses, want to reduce inequalities e.g. improving access to education, health care, life opportunities
- Will be working on this to ensure autistic people have the opportunities they need

**Anna: One of the unwelcome effects of the pandemic is an increase in redundancies. It is very unfortunate but autistic people and other disabled people often seem to be at the front of the queue when redundancies are made – this is despite the requirement to make reasonable adjustments to any selection process. What can be done to redress this unfavourable imbalance?**

- It is unlawful to make someone redundant because of disabilities like autism
- Helping people with complex needs to get into work through work coaches
- Would be open to hearing about cases of systematic discrimination – broader work may be in ensuring autism is understood by society at large
- In short-term, important to work with DWP to support people getting into work

**Jo: What action the Government is taking to address higher coronavirus death rates amongst people with learning disabilities, and therefore the likelihood that autistic people are dying from coronavirus at higher rates than non-autistic people (though there isn't the data to prove it because it isn't collected), and the fact that autistic people in supported living and residential care are being isolated from their families for months on end, because of the blanket application of 'no visiting' rules.**

- There is limited data but we do know there is a higher mortality rate – have commissioned research to understand what is going on and what we can do. Some of this is related to people having other health conditions, and some is related to being in residential settings where the virus can spread
- This has been one of the most troubling things we've seen in pandemic
- Have tried to put things in place to support people in residential settings e.g. weekly testing of care staff, PPE
- Vaccine developments are positive – clinically extremely vulnerable people are at front of queue, which will include people with learning disabilities or autistic people – but not all
- In first spring lockdown, visits were restricted for care homes – this didn't open up as much as hoped or expected in summer
- With new variant, visits have had to be restricted again
- There is now more flexibility for supported living – however difficulty comes from flexibility of settings e.g. some are like care homes and some are more low-risk settings. Hard to have blanket approach but trying to enable sector to understand importance of visiting whilst keeping people safe
- Hope there is not much longer that we will have to live under these restrictions and sector will be encouraged to open up

**Matthew: What compensatory (e.g. summer) educational arrangements will be in place for autistic students and other SEND pupils who have been unable to manage home learning because it has not been delivered interactively by teachers in a fixed schedule and routine? Can we be assured that should further school closures occur, students with such special conditions would have access to interactive teaching by their usual teachers, either in person or on the web?**

- Majority of special schools have stayed open but know not everyone has been able to attend – some children are also in mainstream education
- Have spoken with DfE about ensuring people can access support and can go to school as much as possible – will continue to take this up with Education Minister Vicky Ford

**At the inception of the Coronavirus Act and the Coronavirus Regulations, the Government confused the necessary restrictions on physical proximity to people, with restrictions on leaving one's residence, perhaps because for many non-autistic people the two are equivalent: whereas many autistic people go outside to be alone, many autistic people go outside to meet other people. This policy led to many unnecessary encounters between police and solitary autistic people who already were experiencing anxiety and whose anxiety was exacerbated by police questioning. Can we have positive assurance that, moving forward, people will be allowed to be alone so that they can manage social anxiety? This ability to be alone is especially necessary as an antidote to an environment where other people unpredictably break distancing rules, e.g. after visiting a crowded supermarket or a school run.**

- Important that people aren't stopped when there is no need for them to be. Will take this away and look at what more can be done to address this.

### **Closing remarks from Dame Cheryl Gillan**

- Have had over 100 people on the call at points
- Hope that the Minister will take these issues away and they will feed into Government's work
- Picked up some specific issues:
  - o Masks: this is important for autistic people – see-through masks can be helpful. Will continue to raise importance of understanding masks aren't possible for everyone in responses
  - o Staying at home has been positive for some people – but has disrupted many people's routines
  - o Need to have a plan for communicating pandemic and restrictions to people
  - o Important to remember it is not just autistic children, but adults too – it is worrying to think of mental health impact
- In chairing this group, have ambition for anyone who is public facing to have autism training e.g. MPs, doctors

- Good things have happened in recent years – achieved actual legislation for autism support through the Autism Act
- Expect we will continue to face issues as the vaccination programme continues, hope we will see the end of the gaps in special schools and services. Important we get vaccine out to as many people as possible and open up society again
- As we do this, it is important that this whole section of society, which is so valuable and important, do not feel ignored
- Want to end on point around redundancies – autistic people bring many positives to their jobs. DWP should focus on this e.g. through videos showing the positives
- Would like to see issues raised in chat put together in a letter to the Minister – BAME are important in particular and we must communicate to Minister that support must be fully inclusive
- Thank you to everyone who joined call today – APPGA will be doing what it can in Parliament to ensure autistic people get support they need

**Closing remarks from Secretariat:**

- There will be further meetings planned throughout the year – likely to be virtual
- Hope that for future meetings there will be more notice and information will be sent to attendees earlier